



February 19, 2015

SUBJECT: Proposed H.B. No. 6580 AN ACT ESTABLISHING AN ADVISORY COUNCIL ON RARE DISEASES

TO:

Senator Terry Gerratana

Representative Matt Ritter

Honorable Committee Members:

Thank you for the opportunity to provide written testimony on this very important proposed legislation, H.B.No. 6580. This measure allows for the creation of an advisory council on rare diseases within the state of Connecticut. The United Mitochondrial Disease Foundation (UMDF) is in full support of the creation of this very important advisory council.

Scientific data supports the statistic that up to 4000 people are born each year with a mitochondrial disease. This means that Connecticut could have as many as 3500 residents affected by mitochondrial disease. Mitochondria are in the cells throughout our bodies and they are responsible for changing food and oxygen into the energy needed to sustain life and support growth. When mitochondria malfunction, organs start to fail and people, including children, get sick and even die.

Mitochondrial disease is very difficult to diagnose because it affects every person and every organ differently. Children and adults can have seizures, strokes and severe developmental delays. It is a multi-system disease affecting the ability to walk, talk, see, digest food, and a host of other complications. When three or more organs are affected, mitochondrial disease should always be suspected. Current technology is helping obtain more accurate diagnosis but for many it can still take years to secure an accurate diagnosis. Once a diagnosis is suspected or confirmed, patients are placed on what is called a "mito cocktail" of supplements to help with control their symptoms. The monthly out of pocket costs for continued diagnostics and supplements are very expensive and are not covered under most health care plans.

The creation of this advisory council provides necessary first steps to helping the affected individuals and families in the state of Connecticut. Your actions will begin the dialogue that will pave the way to resolving issues for mitochondrial disease patients as well to many others who suffer with rare diseases. We support H.B.6580 and urge you to do the same.

Your consideration is greatly appreciated,

A handwritten signature in black ink, reading "Chuck M. Nolan Jr." in a cursive script.

CEO/Executive Director

UMDF

8085 Saltsburg Road – Suite 201

Pittsburgh, PA 15239

412.793-8077

chuckm@umdf.org